

# TOWARDS EXCELLENCE IN HOSPICE CARE



*Widening access to  
palliative care for people  
with learning disabilities*

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Guidance and resources  
for professionals

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# Foreword



People with a learning disability have always faced their own challenges, often with determination and courage. However, many of these challenges have been imposed on them, sometimes through indifference but more usually through ignorance. The achievement during the past 60 years of improving their health into adulthood has been tempered by the realisation that they are prone to the same age-related diseases as everybody else, as well as any inherent difficulties they face. Sadly, their march towards equality in mainstream care has not been matched by the ability or willingness of such care services to understand or meet their needs.

In contrast, many learning disability services, organisations and carers have fought hard to defend the rights of people with a learning disability. This has exposed instances of discrimination and inadequate care and demonstrated the level of ignorance that exists about people with a learning disability. This has prompted expressions of strong disapproval from government, but it will be some time before we learn whether such discomfort is matched by improved services. Past experience suggests we will be left with platitudes and demands to improve care within existing budgets, probably with a panoply of new targets.

In the meantime, existing services must continue to drive improvements forward. The role of palliative care is increasingly important as adults and children with learning disability develop life-limiting or life-threatening illness. While some will have cancer, many will have other conditions that will need the support and skills of palliative care services. A key will be the partnership between palliative care and learning disability services, and links between child and adult services; links that have already been successfully forged in many areas. This document is an important step on that path. ”

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# TOWARDS EXCELLENCE IN HOSPICE CARE

# Introduction

Twenty years ago I met my first learning disabled palliative care patient. Maureen was in her early 40s and had been admitted from the local hospital where she was dying from a gastric cancer. Maureen died only four hours after admission having been barely conscious for most of that time. The feeling among hospice staff was of how sad this admission and death had been, and of how much more could have been done had she had been admitted earlier. For myself, although I had seen Maureen I had not been able to communicate with her and I too wished I had met her earlier.

As a social worker my role thereafter was simply to ensure that Maureen's next of kin (an elderly, single mother) was informed of her death. The mother had no telephone and no previous contact with the hospice and so we requested that the local police call on her and deliver this sad news.

The following day I took a call from a Salvation Army officer who sought help for Maureen's mother. Living on her own she had neither the finances nor the ability to organise her daughter's funeral. I agreed to visit the woman and together we organised Maureen's funeral and secured the necessary finance. Then, over a longer period, I provided her with bereavement support.

From the first meeting it was apparent that Maureen's mother also had a learning disability. She lived a quiet, isolated but relatively contented life, supported by the local Salvation Army citadel that had offered her care and a place to stay in one of their hostels until she had gained her own council tenancy where she now lived.

The story of the family life was rich but full of tragedy. However, within that tragedy were also accounts of resilience and the uncommon kindness of strangers. Twenty years previously, from a position of homelessness and the breakdown of Maureen's fragile mental health (into schizophrenia), had come a placement for Maureen in one of the last long-stay hospitals in Scotland. Here Maureen had gained friends, dedicated care, and new skills (becoming an award-winning bowler). Her mother visited her weekly and slowly went on to develop her own life, relieved that her daughter was being taken care of.

In the early 1990s, with the inception of the Community Care Act, it was agreed that women such as Maureen should no longer live in hospital but have their own homes in the community. Maureen had welcomed this and had been housed in a 'core and cluster' flat within a voluntary mental health organisation.

At the tea they hosted following Maureen's funeral, residential care staff were grief-stricken. Perhaps mercifully, Maureen's mother did not fully register these reactions. In talking to staff, it became clear that they were still getting to know Maureen when she had become acutely ill. Warned on admission, by hospital staff, of Maureen's 'attention seeking behaviour' they had not initially taken much notice of her complaints of stomach pain believing it to be as a result of anxiety or difficulty with settling into a new environment. Weeks and months had passed before Maureen became so distressed that she had been taken to hospital where an advanced gastric cancer was diagnosed. It was a short time before her condition deteriorated and she was admitted to hospital, transferred to the hospice and died.

Stories such as Maureen's were not uncommon 20 years ago and, although one might puzzle how dedicated care staff could miss signs and symptoms of such serious illness, few questions were asked and there was little sense that things could be different.

We now know that the explanations for people like Maureen 'falling through the net' are complex. A web of inter-relating factors related to the variant health and disease profiles of people with learning disabilities, the inflexibility of healthcare services to meet the diverse demands upon them, the poor training of mainstream health and social care staff in learning disability and societal prejudices all have their part to play in creating situations which render people with learning disabilities vulnerable. Sadly these factors can result in diagnostic overshadowing, late diagnosis, a failure to treat, and consequently in premature death.

Much has changed for the better in the last 20 years. Policy and service delivery has been transformed to take account of people with learning disabilities' particular needs. For palliative care the development of the English National End of Life Care Strategy <sup>(1)</sup> was an important step forward, highlighting in its equality impact assessment the specific needs of people with learning disabilities. Organisations such as the National Network for Palliative Care of People with Learning Disabilities (now Palliative Care of People with Learning Disabilities Network, see [www.pcpld.org](http://www.pcpld.org)) have highlighted the issues for people with learning disabilities and their carers and have researched, developed and shared best practice.

However, the needs of people with learning disabilities continue to challenge the delivery of palliative care across all the settings in which people

with learning disabilities live and die. The issues are now more sophisticated for although 20 years ago people with learning disabilities were rarely referred to hospices (very often dying shortly after diagnosis) nowadays there are few hospices that have not received and responded to such referrals. However, much of that response has in itself been inequitable with a seductive emphasis on giving 'equal' service. This, while appealing to a natural sense of 'fairness', has not resulted in a 'just' response. Unequal needs require unequal responses tailored to the specific needs of the individual.

Equitable responses to the palliative care needs of people with learning disabilities probably require new models of palliative care as well as 'reasonable adjustments' to the current services that are provided to the majority, non-learning disabled population. Without such adaptations, Swinton's charge of diagnostic overshadowing within palliative care (and the consequent failure to meet the holistic end of life care needs of people with learning disabilities) is fairly meted out on hospices as on other end of life care providers <sup>(2)</sup>.

The good news, however, is that none of these adaptations require rocket science, but rather a revisiting of the fundamentals of palliative care, a focus on the individual, and an attention to detail. Twenty years on, there is a growing community of knowledge, practice and resource seeded within the hospice movement. This publication seeks to draw on that knowledge and to share it with all those working to ensure that the people most vulnerable to being treated inequitably in life are at least treated equitably in their dying.



# Aim and format of the publication

The aim of this publication is to share some of the thinking, good practice and resources that have been developed throughout learning disability and end of life care services in a form that will be accessible to all practitioners but especially those working in hospice settings.

It begins by defining learning disability and the incidence of this disability within the UK population. This is important as there are significant differences between learning disability and other cognitive impairments (e.g. as a result of head injury or dementia) which give rise to specific practice issues. An introduction to the accompanying health issues of people with learning disability begins to set the context within which end of life care issues arise. There are brief sections on the mortality of people with learning disabilities and particular life-limiting illnesses such as cancer and dementia, before we look at the healthcare that people with learning disabilities receive.

Taking the lead from the publication, Widening access to palliative care<sup>(3)</sup>, we then go on to highlight the barriers to care for people with learning disability and follow on with a summary of current policy drivers aimed at addressing these.

The next section deals with palliative care for people with a learning disability. This section covers the issues of cognition and communication, consent, advance care planning, pain and symptom control, psychosocial care (including bereavement), issues for carers, transition and user-involvement, as well as issues for specific groups of people with learning disabilities such as children or those with autism.

The final section of this publication deals with resources and includes information on:

- accessible literature for people with learning disabilities who are dying or bereaved
- dementia resources
- accessible advance care planning tools and resources
- useful organisations
- useful websites
- further reading
- a glossary of terms used throughout the document.

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# Definition and incidence of learning disability

## Definition

Learning disability is ‘a state of arrested or incomplete development of the mind, which includes significant impairment of intelligence and social functioning’ <sup>(4)</sup>. It is also described as ‘a reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and to cope independently (impaired social functioning), which began before adulthood and which has a lasting effect on development’ <sup>(5)</sup>.

Internationally, a number of different terms are used to describe learning disability including ‘learning difficulty’, ‘mental retardation’ and ‘intellectual disability’ (which is the preferred term of the World Health Organization). However, all of these terms commonly indicate a variety of disorders that affect the acquisition, retention, understanding, organisation or use of verbal and/or non-verbal information.

The level of disability varies greatly from one person to another and may be accompanied by a physical disability. The impact of a learning disability may vary according to the accompanying life circumstances of the affected individuals. For some people, partly because of the impairment and partly because of society’s responses to it, this can mean limited life chances or restricted personal networks and an inability to live independently or to develop valued roles. The difficulty with processing or remembering new information may result in the individual finding it hard to adapt to new situations or people. At the most severe end of the spectrum, it may mean that the person is without speech, has little comprehension and is dependent on carers for all aspects of daily living.

Some professionals define learning disability in terms of IQ levels with an IQ of less than 70 signifying learning disability (mild learning disability 50–70, moderate learning disability 35–50, severe learning disability 20–35 and profound learning disability less than 20). It should be noted that many people with an IQ of 70 or below function independently without any additional support or services but may need some extra help when confronted with the challenge of life-threatening illness (see section on Communication, page 14).

## Incidence

There are approximately 1.5 million people in the UK with a learning disability (about 2.5% of the population).

Despite the impact of screening and consequent termination of some pregnancies with genetic abnormalities that result in learning disabilities (eg, Down’s syndrome), the number of people with learning disabilities is growing by about 1.1% of its total population each year. This is mainly because of general improvements in neonatal care resulting in the survival of premature and/or disabled children who previously would have died at birth or in early childhood. The numbers of older people with learning disabilities (over 60s) is growing and is expected to grow by 36% between 2011–2021 with obvious implications for palliative care <sup>(6)</sup>.

The majority of people with a learning disability can now expect to live a near normal lifespan. However, this means that they can also expect to encounter all the diseases associated with ageing, including those requiring palliative care. This section looks at the general health profile of people with a learning disability and focuses on some key research into mortality, incidences of cancer and dementia.

## General profile

People with a learning disability are more likely than non-learning disabled people to suffer from <sup>(7)</sup>:

- obesity – with consequent implications for both heart disease and diabetes (28.3% of the learning disabled population versus 20.4% of the general population) <sup>(8)</sup>
- specific long-term illness or disability (61% versus 31%) <sup>(9-10)</sup>
- epilepsy (22% versus 0.75%) <sup>(11-12)</sup>
- mental disorder (50% versus 25%) <sup>(13)</sup>
- visual disorder (30% of the learning disabled population) <sup>(14)</sup>
- hearing impairment (40% of the learning disabled population) <sup>(15-16)</sup>.

They are also more likely to suffer from respiratory disease, which is the leading cause of death for people with a learning disability (followed by cardiac conditions). While 15.5% of the general population develop respiratory disease, only 17% of these people die of it. In comparison, 19.8% of people with a learning disability develop the disease but about 50% of these die of it <sup>(17-19)</sup>.

Therefore, it is important to take account of all the national service frameworks which have been developed for the entire population, especially those related to coronary heart disease, diabetes and older people.

## Mortality of people with learning disabilities

A Leicestershire-based research study in 2007 looked at mortality patterns in people with learning disabilities over a 13-year period and found that overall mortality was three times higher in people with learning disabilities than in those without. The highest number of deaths were observed in people with profound learning disabilities, people with Down's syndrome and people with learning disabilities living in cities (with women with learning disabilities experiencing higher mortality than their male counterparts living in cities) <sup>(20)</sup>. This echoes earlier research <sup>(21)</sup>.

Other research indicates that people with a learning disability are 58 times more likely to die before the age of 50 than the general population, and are four times more likely to have a preventable cause of death <sup>(22)</sup>.

The most recent report of the Learning Disabilities Observatory on 'How people with learning disabilities die' found that, while only about four in 10 death certificates recorded whether the person had a learning disability, the following was clear:

- All people (of those whose death was officially recorded in England between 2004–2008) with definite or possible learning disabilities died younger than people without.
- People with Down's syndrome commonly die in their 50s and 60s.
- People with hydrocephalus/spina bifida commonly die in their 30s and 40s.
- Some deaths were from possibly preventable causes such as aspiration of food and fluids into the lungs and epilepsy or seizures
- Five percent of people with hydrocephalus died with pressure sores and in three-quarters of these cases this had led to blood infections <sup>(23)</sup>.

## Cancer

Preliminary research <sup>(24-25)</sup> suggests that cancer is less prevalent among people with a learning disability than the general population (16% versus 26%). This research found a lower incidence of cancers of the bronchus, prostate and breast (eg, women with Down's syndrome are up to 25 times less likely to develop breast cancer than the general population).

However, the research also found that people with a learning disability are more at risk from gastric cancers, which account for 58% of cancer deaths in people with learning disabilities but only 25% of cancer deaths in the general population. This may possibly be explained by the higher rate of the bacterial infection *H. pylori* in people with a learning disability, which has been implicated in gastric cancers and lymphomas. In addition, many people who have a learning disability and a physical disability also have postural problems, which cause them to have long-standing gastro-intestinal problems such as gastro-oesophageal reflux disorder. These worsen with age and can lead to cancer.

People with Down's syndrome have been found to be more likely to develop lymphomas and are at a greater risk of childhood leukaemias – although they are much more likely to be cured of the latter because of a genetic mutation that both predisposes them to the leukaemia and enhances the effect of chemotherapy on the disease <sup>(26)</sup>.

Other research found that people who suffer from schizophrenia have a 90% increased chance of developing bowel cancer and women with schizophrenia have a 42% increased chance of developing breast cancer <sup>(27)</sup>. These are important statistics given that people with a learning disability are three times more likely to develop schizophrenia <sup>(28)</sup>.

More research is needed into cancer in people with a learning disability, taking into consideration, among other things, lifestyle factors and the complications that arise around physical conditions that cause both the learning disability and the malignancy, eg, tuberous sclerosis.

## Dementia

People with a learning disability are four times more likely to develop dementia than the general population, irrespective of the cause of their disability. This is even greater for the 20% of people with learning disabilities who have Down's syndrome.

Down's syndrome is a complex condition, caused by a genetic abnormality, which gives rise to a number of physical conditions including cardiac, digestive, skeletal, thyroid, hearing and sight impairments. Despite this, there has been a significant increase in the longevity of people with Down's syndrome, 80% of whom can now expect to live into their 50s <sup>(29)</sup>. However, along with an increased lifespan comes an increased likelihood of developing dementia, with a 55% incidence in those over the age of 60 <sup>(30-31)</sup>. Sadly Alzheimer's disease in people with Down's syndrome has an earlier onset (average age 54 years though many people show symptoms from their 40s) and an average course of five years from diagnosis to death <sup>(32-33)</sup>.

# Healthcare for people with a learning disability

Historically health and social care services have not adequately met the needs of people with a learning disability. This section looks at some of the research into the care they have received, highlights problems and focuses on current government policy.

## Background

Studies have shown that people with a learning disability are poorly served by current NHS services<sup>(34-37)</sup>. They are less likely than the general population to receive health prevention information and some of the important evidence-based treatments and health checks. Often they are subjected to poor communication skills in doctors and nurses, poor coordination of care and geographical inequity of treatment. Additionally, it is increasingly difficult for people with a mild learning disability to meet the criteria required for allocation of health and social care services (eg, a dedicated learning disability nurse or social worker). This is despite anecdotal evidence to suggest that this group are often most challenged by serious illness and/or bereavement.

Although hospices generally perform better than mainstream healthcare settings, a 2001 study found that people with a learning disability who access hospice care were unlikely to be offered the full range of services, especially complementary therapies and hospice day care placements, which were rarely offered<sup>(38)</sup>.

A Mencap study in 1998 reported the experience of one in 10 carers that necessary treatment was not given to people with learning disabilities when in hospital<sup>(39)</sup>. Other studies have also found this with carers reporting that treatment was withheld because either the patient was distressed or healthcare staff assumed they were not able to comply with or consent to treatment<sup>(40)</sup>. Additionally, reports suggest that clinicians sometimes make assumptions about the quality of life of a person with a disability that can then become a clinical judgement about the

value of their life<sup>(41)</sup>. This can result in the clinician not being objective when offering or determining treatment options.

The Mencap study also found that when people with a learning disability were admitted to hospital their carers were expected to stay with them and provide most of their personal care. However, these carers were rarely provided with food or a place to sleep. Information exchange was generally inadequate, and although many patients had special diets, hospitals were reluctant to provide them.

The UK government responded to the Mencap report by carrying out their own reviews of services and developing new strategies<sup>(42-48)</sup>. In particular, in England the 'Valuing people' white paper<sup>(49)</sup> aimed to address the shortcomings identified by Mencap and made the following recommendations:

- A new role of healthcare facilitator to be developed and in place by spring 2003.
- All people with a learning disability to be registered with a GP by 2004.
- All people with a learning disability to have a health action plan by 2005.
- To explore the feasibility of a confidential inquiry into mortality among people with a learning disability.
- NHS to be charged with making sure that all mainstream hospital services are accessible to people with a learning disability.
- All long-stay learning disability hospitals to be closed by 2006.

Despite this government intervention, Mencap highlighted more bad practice in 2007 in 'Death by indifference'<sup>(50)</sup>, a much more damning report detailing the cases of six people with a learning disability who died allegedly 'avoidable deaths' because of the failure of mainstream health services to meet their care needs. The examples given

include someone dying from complications arising from a broken leg, and a death resulting from the hospital not providing adequate alternative nutrition when the patient lost the ability to swallow following a stroke 26 days before their death.

The ‘Death by indifference’ report prompted an independent government inquiry into access to healthcare for people with a learning disability. Led by Sir Jonathan Michael in 2008 the inquiry found that the experiences of the people described in Mencap’s report were by no means isolated. Despite a clear framework of legislation against discrimination, the inquiry uncovered accounts of appalling examples of discrimination, abuse and neglect across the entire range of health services. Sir Jonathan commented:

“Addressing the difficulties faced by people with learning disabilities in accessing general healthcare services does not require specialist knowledge about learning disabilities... What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment. I have also learnt that ‘equal’ does not always mean ‘the same’ and the ‘reasonable adjustments’ that are needed to make services equally accessible to people with learning disabilities, are not particularly difficult to make” <sup>(51)</sup>.

Sir Jonathan made 10 recommendations, including mandatory learning disability training for all healthcare professionals, systems for better regulation and inspection, and greater involvement of people with a learning disability and their carers.

Further to the Michael inquiry, the Health Ombudsman for England, Ann Abraham,

carried out investigations into the six cases detailed in the ‘Death by indifference’ report. She found significant and distressing failures in health and social care services and that, on occasion, people with a learning disability experienced prolonged suffering and inappropriate care for disability-related reasons. The Ombudsman concluded that”

“The understanding of the needs of people with a learning disability among health and social care services is at best patchy and at worst an indictment of our society.”

The Ombudsman recommended that NHS and social care organisations in England urgently review the effectiveness of the systems and services they have in place <sup>(52)</sup>. Since then the Norah Fry Research Centre has been charged with carrying out an investigation into premature deaths of people with learning disabilities. Begun in 2010, government funding has been extended to allow this investigation to be carried out until 2013 <sup>(53)</sup>.

## Barriers to care

Several areas of health and social care practice result in poor quality of care for people with a learning disability, as shown below.

### Access to screening services

People with a learning disability are often excluded from screening services. For instance, a 1998 Mencap study <sup>(54)</sup> found that cervical screening was accessed by 85% of women from the general population who were eligible, compared to just 17% of women with a learning disability (and this fell dramatically to 3% for women living at home). Breast screening figures were somewhat better, with 50% of women with a learning disability who were eligible accessing it, compared to 76% of women from the general population (though this



fell to 17% for women with a learning disability living at home). When explicitly offered breast screening, more than 90% of women with a learning disability took up this offer, undermining any assertion that they may be apathetic about their health. The Department of Health subsequently funded work that resulted in good practice guidelines being developed in this area <sup>(55)</sup>. In recent years health facilitation nurses have sought to increase the numbers of people with learning disabilities who access routine screening services such as those for breast, cervical and bowel cancers <sup>(56)</sup>.

### Communication problems

Often health and social care professionals do not recognise that someone has a learning disability, especially when a patient is more verbally competent than they are cognitively. As a result, they are unlikely to be aware that a patient is struggling to understand the significance of complex new information, especially when the information is delivered by several professionals, each working within distinct care models across a number of care settings and with their own professional language and jargon. If a patient shows frustration at not being able to understand the information, they may be misunderstood as being difficult or aggressive.

In cases where the professional is aware that a patient has a learning disability, frequently the patient is overlooked and ignored. A small-scale audit <sup>(57)</sup> found that in the vast majority of cases, medical and nursing staff did not discuss the diagnosis of serious illness and treatment options directly with the patient or relative with a learning disability. The discussion was usually with an informal or formal carer, who was then left to decide what information, if any, to pass on.

The other major communication difficulty is related to the expression of distress. Many people with a learning disability express distress through physical signs and behaviours rather than verbally, even if they routinely use speech. In people with a more severe learning disability, their ability to conceptualise and understand their own body may be impaired and consequently they may not be able to convey that they have pain or be able to identify its cause, its location or severity.

Research has shown that carers of people with a learning disability regularly identify distress but find it difficult to interpret its cause. They often have little confidence in their observations and may find it difficult to convey them to healthcare professionals who do not know the patient and who may have little experience of working with people with a learning disability <sup>(58)</sup>.

### Differential diagnosis

Healthcare professionals dealing with learning disabled patients sometimes fail to make a differentiation between the possible diagnostic options within a range of conditions or diseases <sup>(59)</sup>. This may be related to the limited contact they have with people with a learning disability and/or a lack of training. As a result, they are not able to make distinctions between different types of learning disability and associated syndromes; distinctions that would enable them to facilitate the most appropriate treatment.

There are significant challenges for medical staff in arriving at a differential diagnosis of dementia in people with learning disabilities, especially in those who have a pre-existing mental health condition <sup>(60-62)</sup>. However, learning disability staff, particularly those working with people with Down's syndrome, are becoming increasingly skilled in this area. There are now many examples of proactive screening for dementia and resources are being developed to help staff deliver end of life care to people with learning disabilities who have dementia (see resources section on page 36).

## Diagnostic overshadowing

Diagnostic overshadowing is very common in the medical and nursing assessment of people with a learning disability; healthcare professionals assume that a person's symptoms are a result of their learning disability instead of physical illness. Carers report being told: "They have a learning disability so you have to expect this" <sup>(63)</sup>.

The implications of this are extremely serious and often account for the late diagnosis of malignancies, which reduces the options for curative treatment, as demonstrated by the 'Death by indifference' report <sup>(64)</sup>.

## Care setting

Many people with a learning disability live in social care settings where the care staff are often unqualified and have no background training that would enable them to recognise the early signs of serious ill health. Recent research concluded that while care staff provide invaluable support in communication with people with a learning disability, they need help with recognising symptoms <sup>(65)</sup>. This echoes findings of previous research, which found that 24% of carers reported that their clients had no symptoms, despite them actually having an average of 5.4 <sup>(66)</sup>.

The healthcare of people living in social-care settings can be complicated by the registration status of the home (ie, whether it provides nursing care), the needs of the other residents, the conflicting views of carers, advocates and family members, and the lack of healthcare skills among the staff. However, there are examples that show how close cooperation between everyone involved and mutual sharing of expertise can result in good care for terminally ill patients, regardless of the registration status of where they are living <sup>(67)</sup>.

There are also specific issues for people who live in medium secure units, detained under the Mental Health Act (sometimes referred to as being

'sectioned'). People in these settings are sometimes hundreds of miles away from their families, which has implications for interpreting 'normal' behaviour and assessing pain. Often people in this situation are treated with multiple medications, which, if altered, could affect their mental health, creating difficulties for healthcare professionals trying to treat their pain. Staff in these settings (some of which are in the private healthcare sector) are unlikely to have general healthcare skills and are often unaware of what residents have a right to expect from primary care services.

Given the over-representation of people with learning disabilities in the prison population, and because this is an ageing population, it is likely that there will be specific issues also for these establishments during the next few years. However, there is currently no literature specific to learning disability to draw on to guide practice in this area of care.

## Recent developments

The government's most recent (English) policy document, 'Valuing people now: a new three-year strategy for people with learning disabilities' <sup>(68)</sup>, was launched in January 2009 after a consultation with more than 10,000 people. It sets out a number of aims, which include:

- ensuring people with a learning disability get the healthcare they need and the support they want to live healthy lives
- supporting more people with a learning disability, including those with more complex needs, into paid work
- making sure people with a learning disability have the choice to develop relationships, become parents and continue to be parents
- giving people with a learning disability opportunity to study and enjoy leisure and social activities.



The strategy also includes the government's response to Sir Jonathan Michael's 'Healthcare for all' report and commits to:

- establishing a confidential inquiry to investigate the premature deaths of people with a learning disability
- commissioning a new Public Health Observatory to provide essential data information at a national and local level
- working with the professional regulatory bodies to make sure medical students and NHS professionals receive training on learning disabilities, equalities and human rights.

In 2009, the Care Quality Commission (CQC) announced that it would be taking steps to better scrutinise the care of people with a learning disability by building intelligence networks within services, representative groups and other relevant organisations. It is intended that this will then feed into the regulator's inspection of services. It also announced plans to:

- hold a special review of physical healthcare for people with a learning disability and people with mental illness, in response to the Michael inquiry
- pilot a joint service inspection of local authorities and primary care trusts to check adult safeguarding mechanisms
- consult on a special review on the use of restraint and the health and social care needs of offenders who have learning disabilities
- involve 'experts by experience' (people with a learning disability and carers) in a range of health and social care inspections and reviews, including having a person with a learning disability working on the CQC team
- continue to work with the Department of Health to improve available data, including performance indicators and the possibility of having a national minimum data set for learning disabilities <sup>(69)</sup>.

# TOWARDS EXCELLENCE IN HOSPICE CARE



# Palliative care for people with a learning disability

People with a learning disability and a life-limiting or terminal illness should be able to access the same quality of palliative care as the general population. This section looks at some of the key issues and areas of practice that palliative care professionals need to consider to make sure this access is achieved.

## Cognition and communication

Issues related to cognition and communication are important to consider when offering palliative care to people with a learning disability as they are likely to influence most elements of care. While communication is often complex and challenging, health and social care staff are professionally obliged to communicate directly with patients and/or carers who have a learning disability.

As not all incidences of learning disability are recorded, and some families may have actively sought to avoid the stigma associated with this label, it is possible that some learning disabled service users will not formally be identified as such. It is important therefore to consider what other indicators there might be of learning disability and to think about how to frame questions to check any suspicion that a patient, though verbally competent, has a learning disability or an autistic spectrum disorder.

## Understanding of death and dying

Some adults with a learning disability (depending on its severity) may never reach a full understanding of a complex concept such as death (which includes ideas of non-functionality, permanence, universality, inevitability and causation)<sup>(70-73)</sup>. This is especially true of people who grew up in an institutional setting (such as a long-stay hospital<sup>(74)</sup>) who may have been 'protected' from such knowledge. This may present challenges when communicating with such a patient or relative about the life-threatening aspects of a diagnosis.

**Case study:** The angry outbursts of Gregor some six months after the death of his mother were uncharacteristic and consequently prompted a referral for bereavement counselling. During the sessions with his counsellor, Gregor was able to talk about his complex relationship with his mother. He loved her and she him, but it was clear that sometimes she had found the sole care of her boisterous son difficult. Gregor's strength at times outweighed his ability to think through the consequences of his actions and sometimes, in frustration, she would say to him, "You're nothing but a pest and I am going to leave you". When she died, Gregor believed that she had done just that.

On exploring Gregor's concept of death it became clear that although he understood many things he had not understood that the serious illness that his mother had would lead to her death, even though he had visited her many times when she was ill. Helping Gregor to understand the link between serious illness and death helped him to understand that his mother had no choice over leaving him. Slowly he came to understand this and to grieve appropriately the loss of his mum. As he did so, the anger subsided to make way for his sadness at the death of his mum.

Assumptions should not be made about the person's understanding. It is important to explore the person's earlier experiences of illness and death, in order to find out if they have linked concepts (such as serious illness leading to death), and take into account their understanding of the concept of time. If someone does not have an accurate understanding of time, it may not be appropriate to discuss prognosis at an early stage (unless directly asked). To do so could lead to the person experiencing extreme distress because they think an event is imminent when it is actually several months away<sup>(75)</sup>.

Great care also needs to be taken about the type of language used to explain serious illness and death. Some people with a learning disability apply a very literal understanding to abstract concepts, which can lead to confusion and increased fear. For example, someone having a procedure that involves a radioactive dye injection may understand it to be a 'die' injection and become distressed. Current models for breaking bad news have to take sufficient account of the complexities of working with someone with a cognitive deficit <sup>(76)</sup>.

### Non-verbal communication

Communication is even more difficult when a patient does not speak, though many people with a learning disability who do not speak can understand verbal language and, in the correct context, convey that understanding. To make sure these people receive the appropriate care, Makaton or Signalong signers and communication professionals (eg, speech and language therapists) should be involved, as they can enable people to communicate using assistive communication aids. In the short term, it may be appropriate to use the services of an informal or formal carer who understands the significance of any distinctive gestures the patient makes. However, the same ethical complexities apply as when using carers to interpret for someone whose first language is not English, and it should be remembered that it could be incredibly distressing for people with a close relationship to the person to explain the harsh realities of limited prognosis.

### Consent

The Mental Capacity Act (2005) <sup>(77)</sup>, which covers England and Wales, and the Adults with Mental Incapacity (Scotland) Act 2000 <sup>(78)</sup>, give clear guidance on issues related to consent to treatment and all organisations are legally bound to comply with these; the various guidance documents are helpful in developing best practice for individual organisations <sup>(79)</sup>.

Generally, in law for anyone to be considered to have capacity to consent to or refuse treatment they must be able to:

- remember and retain the information relevant to the decision in question
- believe the information they receive
- weigh the information they receive to arrive at a choice
- communicate their decision <sup>(80)</sup>.

Practitioners are advised to consider that:

- Everyone should be presumed to be competent unless proven otherwise, ie, not presumed to be incompetent even if they have a learning disability.
- People are not universally competent, ie, it is possible to be competent to consent to the removal of a painful decayed tooth while simultaneously not being competent to consent to palliative chemotherapy.
- No one can consent to treatment on behalf of another adult (incapacitated or not).
- Incapacity in and of itself does not constitute grounds for refusing to give medical treatment as doctors are required to act in the 'best interests' of a patient irrespective of the patient's ability to consent.

With regard to people with learning disabilities, one has to consider that whilst the same legislation and guidance apply, there may be additional practice considerations when working with people who may not necessarily have lost capacity but who may never have had full capacity <sup>(81)</sup>. The Department of Health guidance on consent as it relates to people with learning disabilities is very helpful in this regard <sup>(82)</sup>.



One of the main challenges in dealing with issues of consent is not just whether a patient is able to consent, but whether they are able to demonstrate this ability to consent. Although a patient may have the cognitive ability to make an informed choice, they may not have the communication or social skills to demonstrate this. It may require significant effort to meet the requirement to:

**“Provide the patient with all appropriate help and support to maximise their ability to understand, retain, use or weigh up the information needed to make that decision or communicate their wishes”<sup>(83)</sup>.**

This is further complicated by the fact that many people with a learning disability have never been allowed to make decisions about any aspect of their life. Therefore, they may not have the experience or confidence to make choices, irrespective of their cognitive ability. Palliative care professionals will need to show patience and great sensitivity to enable someone in that situation to think through their options, arrive at a choice and communicate that choice clearly<sup>(84)</sup>.

It is important to remember that decisions (and indeed the ability to consent) need to be reviewed as situations change. Many people may change long-held beliefs when faced with a debilitating or painful illness, or when facing seemingly non-effective treatments. There is no reason to assume that this should be any different for someone with a learning disability<sup>(85)</sup>.

It is advisable to make links with local learning disability advocacy groups, which often have a wealth of experience in enabling people with a learning disability to both make and demonstrate their decisions. English palliative care professionals should also be proactive about making links with their local independent mental capacity advocates (IMCAs) – a group of professionals who may be

called on, within the scope and funding of the Mental Capacity Act, to represent the views of a person who has no one else to represent them. IMCAs are currently positioned in the community rather than in the hospice. However, since on average 90% of the last year of a patient's life is spent at home, specialist palliative care staff are likely to face complex decision-making in the homes of patients with a learning disability.

#### **St Christopher's Hospice Community Nurse Team case study:**

A middle-aged learning-disabled woman with an oesophageal cancer and long-standing mental health problems was referred to her local hospice. The hospice clinical nurse specialist (CNS) made an assessment visit to the flat where the woman lived relatively independently served by staff in the daytime but living alone in the evening.

On this visit it became clear that the woman's rapidly deteriorating physical condition, fluctuating mental health needs and learning disability meant that there was a continual need to be considering what was in the 'best interests' of this lady. As a result, a meeting of the multi-professional, multi-agency team was called by the hospice CNS and it was agreed that this group should meet thereafter on a monthly basis to consider the issues as they arose.

Where the patient was considered to have the requisite capacity for a decision this was complied with – even in situations where the wisdom of it might have been questioned. For instance, the woman continued to eat only dry and starchy foods, which were likely to cause problems for her physical condition but which she was clear she did not want to change. However, when it came to a decision concerning whether an oesophageal stent should be inserted it was clear this was beyond the patient's understanding (and the formal assessment of her capacity confirmed this) and so a 'best interests' meeting was called to consider the procedure.

The team worked with the woman to clarify her wishes at each step of the way, and as a result, her care was managed at home for the majority of her illness. Early in the illness, the woman had insisted that she wanted to die at home and the team helped her to understand that this might mean that she would be on her own if it happened during the night. Understanding this she still expressed the wish to remain at home. The team then supported the individual daytime workers to consider how they would cope if they should come on duty to discover that the patient had died in the night and consequently everything was arranged for this eventuality. However, close to the end of her life the patient changed her mind and decided that she would rather be cared for in the hospice, which she had viewed early on in her illness. Therefore, she was admitted during the last week of her life and died there peacefully.

A number of resources have been developed to support practitioners in matters of capacity as it relates to end of life care decision-making. These include:

- Help the Hospices website [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk) which has sections on the MCA and an e-learning resource.
- The Social Care Inspection for Excellence (SCIE) website [www.scie.org.uk](http://www.scie.org.uk) signposts to a wide range of resources including their commissioned publication 'Best Interests at End of Life' <sup>(86)</sup>, see bullet below.
- The General Medical Council publication 'Treatment and care towards the end of life: good practice in decision making' (2010) <sup>(87)</sup>.
- Best Interests at End of life: Practical Guidance for Best Interests Decision Making and Care Planning at End of Life, Hutchinson C., Foster J (2008) <sup>(88)</sup>.

## Advance care planning

The End of Life Care Strategy for England <sup>(89)</sup> makes it clear that people with a learning disability (as identified in the equality impact assessment section) should have the same choices around their end of life care and place of death as the general population. To facilitate this, it is important to undertake good, proactive advance care planning, using the available tools and pathways including the Gold Standards Framework and the Preferred Priorities for Care <sup>(90)</sup>. Some practitioners (mainly those from a learning disability background) have developed accessible versions of these tools and supporting resources working from a person-centred perspective <sup>(91)</sup>. The recent 'Routes to success in end of life care' publication on end of life care for people with learning disabilities also provides useful guidance on issues at each stage of the end of life care pathway <sup>(92)</sup>.

To ensure people's wishes are expressed, recorded and achieved the planning work needs to begin as early as possible after initial contact with the patient to make sure they are given the time they need to gradually understand the situation. Cognisance needs to be given to the person's conceptualisation of time and previous experience of serious illness in preparing them to understand the full implications of their prognosis.

High standards of coordinated care and multidisciplinary working are essential to achieve the best outcome for the patient. Some teams have found it useful to schedule regular 'best interests' meetings with everyone involved (including informal carers and the patient where possible). These meetings also help to make sure that the package of care is flexible enough to be changed in line with the evolving wishes of the patient.

**Dorothy House case study:** Dorothy House Hospice in Bradford on Avon has for a number of years tried to address the needs of people with learning disabilities. One of the ways in which they have done this is to appoint a nurse educator into the role of practice facilitator for people with learning disabilities.

The practice facilitator has developed links with learning disability professionals and user groups, and the education and support needs of the sector have been scoped and courses tailor-made to meet them.

The practice facilitator has undertaken work with staff groups where one of their users is terminally ill to facilitate their thinking around planning for end of life care. Combining the person-centred and essential lifestyle planning models that are familiar to learning disability staff with advance care planning models, she has enabled staff to consider those things that are important for the person (those elements for which they have a duty of care) and those things that are important to the person. This empowers the staff to work with the service user to develop their own unique end of life care plan and gives staff a clear agenda to work to in the last days of the person's life, thereby enhancing the chances that the individual will have a 'good death'.

A growing number of people with a learning disability live independently in their own homes, supported by community nurses, advocates and carers or friends. These people are the most vulnerable to being moved against their wishes if they develop a terminal illness. While it should not be assumed that 'home' is the best place for these people to die, many people with a learning disability greatly value their independence and may prefer to die alone rather than give up this achieved 'home of their own' at the end of their lives. This highlights the need for planning and trusting relationships so that the patient can be helped to think clearly about what the various options mean and how best to choose between them.

## Pain and symptom control

Assessing pain in people who have a learning disability can be difficult, and there are contrasting theories as to how a learning disability may affect sensitivity to pain. Some researchers have found varying levels of reduced sensitivity to pain in people with severe learning disabilities, while others have suggested that 25% of people with a learning disability experience increased sensitivity to pain<sup>(93)</sup>. A significant number of people with learning disabilities experience needle phobias and anxiety related to a range of medical interventions that may increase their sensation of pain and distress. Many people with a learning disability and a non-malignant condition (including Alzheimer's disease) will experience the same levels of pain as those with cancer<sup>(94)</sup>.

What is known is that people with a learning disability are more likely to express pain and distress behaviourally than verbally. Some of this expression is very difficult to interpret as it may be expressed through challenging behaviour or self-injury as well as through behaviours such as rocking or crying which are more common indicators of pain. When idiosyncratic signs and behaviours communicate distress, it is crucial that these are interpreted correctly. Therefore, it is essential to include a patient's carer in any assessment. The DisDAT tool is also an invaluable assessment resource<sup>(95-96)</sup>.

Controlling pain and other symptoms is as complex as diagnosing them. Many of the medications currently used in palliative care for the treatment of pain are also used in the psychiatric care of people with a learning disability. The complex range of syndromes and physical and mental conditions people with a learning disability experience mean the control of their symptoms may require the expertise of specialist palliative care practitioners in partnership with their learning disability colleagues. Innovative uses of sensory stimulation such as Snoezelen may be helpful in minimising distress.



## Psychosocial care

“Psychosocial care addresses the psychological experiences of loss and facing death for the patient and their impact on those close to them. It involves the spiritual beliefs, culture, and values of those concerned and the social factors that influence the experience.” David Jeffrey

He would suggest that psychosocial care encompasses:

- Psychological approaches, which are concerned with enabling patients and those close to them to express thoughts, feelings, and concerns relating to illness.
- Psychological interventions to improve the psychological and emotional wellbeing of the patient and their family and carers<sup>(97)</sup>.

Psychosocial care would be seen by many to be a defining element of palliative care, as against other types of medical or nursing care, and yet it is probably the area which is most inaccessible to people with learning disabilities. Studies would suggest that even when people with learning disabilities access specialist palliative care they are unlikely to be offered the ‘softer’ elements of this care such as complementary therapies and/or counselling interventions (especially bereavement counselling)<sup>(98)</sup>. Professor Swinton suggests that within palliative care people with learning disabilities are subject to a particular type of ‘diagnostic overshadowing’ whereby the sole focus is placed on the physical needs of the patient but no consideration is given to the emotional, spiritual or psychological concerns<sup>(99)</sup>. Thus, people with learning disabilities may experience uneven access to services. They may appear within the statistics for referrals to a particular service, but if their journey through the service is mapped it becomes apparent that it varies in the range of interventions offered.

## Psychological or emotional care

Undoubtedly one of the reasons that palliative care staff are so challenged in providing good psychosocial care to people with learning disabilities is that so little is known and written concerning the emotional world of people with such disabilities. Psychotherapy for people with learning disabilities is still a relatively recent discipline (there having been a prevalent belief that people with learning disabilities could not engage effectively with this type of thinking), however, the emerging literature over the last 20 years is very rich and has obvious application in end of life care<sup>(100)</sup>. Recent publications apply this type of thinking to the bereavement care of adults with learning disabilities<sup>(101-102)</sup>.

Despite this it should be remembered that many of the interventions, which are routinely used with non-learning-disabled patients, could easily be adapted for work with people with learning disabilities. For instance, those who are used to working with structured life review<sup>(103-104)</sup> might want to combine this approach with that used in the compilation of a life story book<sup>(105)</sup> to simplify the approach whilst enabling people to benefit from the processes integral to life review. The creation of memory boxes or writing letters can all be undertaken relatively straightforwardly.

As with all people, patients who have a learning disability may have a ‘bucket list’ of things they wish to do before they die, and as with other people, this needs to be explored. However, issues related to dependency, risk and possible ‘over-protection’ may all need to be navigated.

In any intervention undertaken consideration needs to be given to the developmental stage of thinking that the person with a learning disability may be at, as do issues related to emotional attachment. The work undertaken here is vitally important in enabling people to develop and express their resilience in dealing with issues related to the end of life and bereavement.

**Case study:** When Sally was admitted to the oncology ward it seemed inconceivable that she would cope with the complexities of an open and busy ward setting. Having suffered panic attacks and obsessive-compulsive behavior since the age of five, she had no peers or close friends, her only confidants were her mother and stepfather. Sally, although middle-aged, had never had an intimate relationship and she struggled with the inevitable examinations her breast cancer brought. She confided in the palliative care counsellor that the fungating tumour made her feel dirty and ugly, and that she was ashamed of it.

Over the last weeks of her life, time away from the strictures of family life allowed her the space to explore what her life had meant. She discussed the loneliness she had experienced since early childhood; educated in mainstream schooling she had struggled to make friends and had never been invited back to anyone's home and did not have the confidence to invite others to come to hers. As an adult she had been shy and rarely went anywhere without her parents and consequently never made her own circle of friends. She talked of her obsessive-compulsive disorder and the comfort that her 'habits' had brought her in a world which she found frightening and largely rejecting of her. However, of all the sophisticated interventions that the palliative care team undertook for her, it was the gentle, dignified approach that a more junior male nurse regularly took in providing her personal care that wrought the greatest change. Sally found this the most healing of all those things that she experienced and said that although she was sad to be dying, she believed that 'another time' her life would have 'come right' and that she could have had a boyfriend, husband and maybe her own children. The dignity with which she had been treated in the less than perfect ward setting had given her a completely new understanding of herself and of the possibilities for her life. She felt and expressed a deep affection for the small group of staff who supported her in her last days and this was reciprocated in the deep connections staff felt towards her.

## Spiritual care

Spirituality is very important to many people with a learning disability, and while the language used to help them express their spiritual ideas may need to be simplified, the concepts are just as multifaceted as for the general population <sup>(106)</sup>.

People with a learning disability often express a fundamental need for connection to someone external; this may be satisfied by a religious belief. For them, spirituality provides a means of finding hope, strength and security, to help them cope with life; a unifying force that links past, present and future, helping them to continue bonds with people who have died; giving a sense of belonging and solace for their loneliness and disconnectedness. However, research has shown that they are often not given the opportunity to discuss their spirituality despite consistently expressing a wish to do so <sup>(107)</sup>.

Very little work has been done to explore the spiritual lives of people with a learning disability specifically from the palliative care perspective. Case studies that have been gathered for other purposes are suggestive of, for instance, the expression of 'total pain' <sup>(108)</sup>, but these need to be developed significantly if people with a learning disability are to have their holistic palliative care needs fully met.

There are a number of resources on the Foundation for People with Learning Disabilities website that may help with the provision of appropriate spiritual care. See the resources section on page 36 for further details.

## Carer issues

The rights of carers have been high on the government's agenda in recent years. In 2008, it launched a national strategy for carers <sup>(109)</sup>, which sets out proposals to support carers with every aspect of their caring role and to allow them to have a life of their own. The strategy, which applies in full to England but also contains elements that apply throughout the UK, is part of the New Deal for

Carers, which has identified carers of people nearing the end of life as a priority target group. The End of Life Care Strategy for England also recognises the important role carers play in providing care.

For people with a learning disability, a carer could be a family member (often a sibling or parent), their partner or friend who also has a learning disability, or a paid carer (either professional or unqualified).

### Family carers

Many family carers live in very demanding situations and often do not get the support they need <sup>(110)</sup>. A 2001 study <sup>(111)</sup> of people who care for a relative with a learning disability found that:

- 60% of parents spent more than 10 hours per day on basic physical care
- parents were woken up three times per night on average
- 48% received no support from outside the family to help with their care
- 78% received either no support or less than two hours support per week to help them care at home
- 48% were dissatisfied overall with the services they received
- 80% thought the professionals they had contact with were poorly or very poorly coordinated
- 37% had contact with eight or more professionals
- 54% of parents said they would like to see their grown-up son or daughter move from the family home to a high-quality alternative, but 61% had received no support in planning for that possibility.

More than 29,000 adults with a learning disability live in their family home and are cared for by an elderly parent (70 years or above) <sup>(112-113)</sup>. If a person in this situation develops a terminal condition, it may be almost impossible for their carer to provide any more physical care, resulting in the patient being moved to another care setting. This can be distressing for everyone involved, and the fear of this happening, alongside concern about who will look after their 'child' when they die, sometimes leads to parents resisting either curative or prolonging treatments for their son or daughter. This has to be dealt with sensitively.

It is important to be aware of the variant 'burden' of care and the levels of isolation and poverty that many long-term carers in this situation face. They may also be disillusioned with or fearful of professional carers because of previous negative experiences and therefore may need time to develop trusting relationships with new health and social care professionals.

As well as older family carers, there are also a large number of adult sibling carers. Some sibling carers will have been sharing the care of their brother or sister since they were children themselves; to some extent, their lives will have been shaped (both positively and negatively) by this experience <sup>(114)</sup>.

**Case study:** Margaret Fray is the author of 'Caring for Kathleen', which details her life and that of her sister Kathleen who had Down's syndrome. Kathleen was born at a time when the statutory education of people with learning disabilities was not compulsory and so Kathleen was taught to read, write and count by her mother, and to dance and cross-stitch. Kathleen was a loved member of both her family and community and her cross-stitch is still displayed in a Lancashire museum.

When Kathleen was in her 60s she was diagnosed with Alzheimer's disease and as a result became immobile, mute and doubly incontinent. Margaret describes the deep sorrow she felt in witnessing the loss of skills that Kathleen had struggled so hard to develop.

Kathleen died in 1997 just before her 70th birthday; Margaret had cared for her for most of her life, first alongside her mother and latterly with the support of her partner. This caring had involved all aspects of life including physical, emotional and practical care, hosting wonderful birthday parties and latterly petitioning her local MP to ensure that Kathleen was able to die in her 'preferred place of care'. Margaret, now in her 80s, continues to advocate for equal rights in the care of people with learning disabilities (see 'Caring for Kathleen', BILD)

Apart from the practical care and support that siblings may need, it is important to remember that there may be complex emotional dynamics that affect their ability to deal with the terminal illness and death of their brother or sister. Some may have had limited contact with their sibling because either they moved away from home early or their sibling was admitted to a learning disability hospital as a child. They may not have had close contact until the death or illness of their parents, or even until the final stage of their sibling's life. As a result, there may be issues related to attachment, anger, guilt or ambivalence, which may reappear during this stressful time. In this situation, there is a need for proactive responses to facilitate the expression of unresolved issues both prior to death and in bereavement. Kissane and Bloch's model of pre-bereavement family work may be applicable in this situation <sup>(115)</sup>.

It should not be assumed that a patient with a well-established network of carers needs less palliative care intervention (especially around discussing death and dying). Even highly skilled learning disability professionals may find it very difficult to talk about death and dying, and family members may have spent a lifetime protecting their loved one from the knowledge of their disability and mortality.

## Carers with a learning disability

Some carers will have a learning disability themselves, but it should not be assumed that this makes them incapable of providing adequate care. There are many such carers of elderly parents who manage with relatively little support <sup>(116-117)</sup>.

The Foundation for People with Learning Disabilities identified the following issues for people with a learning disability who are carers:

- They feel proud of helping out and returning the care and support that has been provided to them by their parents for so many years.
- There is great teamwork between the family members.
- Generally, they are not recognised for their role as carers.
- They are not always offered many choices about continuing to care or the way that other support is being provided.
- There is fear from both the person with a learning disability and the older family carer of being judged and separated if workers discover the extent of the mutual caring that is happening.
- There is a lack of accessible and easy-to-understand information on people's rights as carers, support that might be available, and the different health conditions that their elderly relative may be suffering with.
- There is a lack of practical support with some tasks that could make a big difference, eg, shopping, changing light bulbs, getting to appointments, and getting the right benefits.
- They feel very isolated and have reduced opportunities for friendship and breaks.

**Case study:** Daniel was in his early 30s and had a mild learning disability. He lived in the family home with his parents and worked part-time in a local grocer's shop. After Daniel's mother died, he became the main carer for his father who was frail and increasingly housebound. Daniel undertook the shopping, cooking and housework with support from a home help. Daniel's older siblings visited irregularly and when they did, they were often critical of the care which Daniel provided.

When Daniel's father was diagnosed with advanced cancer, he was referred to the local hospice. At the end of his life, Daniel's father was admitted for hospice inpatient care. Daniel's siblings visited their father in the hospice frequently. Daniel visited whenever a member of the family took him or at the weekend when he was not working and could manage to get there by public transport.

Although Daniel had been the sole carer for his father he was not consulted about his future care and when his father died (despite having asked to be told by staff) the staff deferred to the wishes of the older sibling who asked to be told first and who then said she would tell Daniel. Daniel was very distressed by this, as he felt that he was the person who had most looked after his dad and that he should have been told. Instead he was told by his sister who had always been unkind towards him.

If a carer has a learning disability, it is important not to override the natural hierarchies of relationships, e.g. by consulting a non-disabled family member or friend rather than a life partner who has a learning disability. Family support teams will need to be proactive in helping the patient identify who they want to care for them and whom they consider their proxy decision maker or next of kin. Documenting these conversations is vital.

**Case study:** John (who had a moderate learning disability) had lived with his girlfriend, Susan (who also had a learning disability) for about 10 years in a council flat. When, after a short hospital admission, John was found to have extensive cancer his family were called for a case conference. John's older brother attended the conference and said that John should not be told he had cancer, as he would be terrified. He also said that Susan should not be told as she may deliberately or inadvertently (because of her learning disability) tell John. John's prognosis was very poor and he was admitted to hospital less than two months later, deteriorated suddenly and died within a few days. Susan was very shocked and distressed by this 'sudden death' for which she had not been prepared.

If a patient has complex palliative care needs, there will be a need for proactive planning by everyone involved in their care. It can be tempting to offer inpatient admission as a first, rather than last, resort. However, this may not be helpful in the long term to any of the people involved and may increase the complexity of the bereavement experienced by the carer who has a learning disability. As with any complex situation, robust risk analysis needs to be undertaken, but with a little extra support and some adaptations (eg, programming the key worker's number into the fast dial facility of the home or mobile phone), the care of the patient may be able to be managed at home.

The 'Who cares for us?' campaign aims to highlight the issues for carers who have a learning disability. For further information visit [www.inspiredservices.org.uk](http://www.inspiredservices.org.uk)



## Bereavement

The bereavement experience of people with a learning disability is often complex. There are several reasons for this:

- They usually experience higher levels of loss and separation than the general population, but poor recording of social history in care settings means that carers will often not know about previous losses and therefore cannot check whether these are fully resolved.
- There may be early attachment difficulties, initiated by the disability, which may influence current experiences of loss <sup>(118-119)</sup>.
- Many people with a learning disability are not informed of the impending death of a relative, which leads to the death being experienced as a 'sudden death', making it more traumatic.
- Cognitive difficulties may lead to misunderstandings about the death, which can intensify grief, eg, some people do not make the link between terminal illness and the inevitability of death and therefore may experience the death as 'abandonment' or 'desertion' <sup>(120)</sup>.
- It is common for people with a learning disability to be refused access to the 'rites of passage' that facilitate healthy grief (eg, planning the funeral). Research into funeral rites found that less than 50% of people with a learning disability attended their parents' funerals <sup>(121)</sup>.
- Care staff may have had little or no training in bereavement care and therefore may miss signs of deep distress. As grief is often expressed behaviourally (rather than verbally) this can result in care staff failing to make a link between, for example, challenging behaviour and the bereavement. This can be the case even when the loss is well known and documented <sup>(122)</sup>.

- Grief may be delayed in some people with a learning disability. Therefore, carers may not link current distress with a loss that may have happened six months or even a year or two ago.
- People with learning disabilities may have less well-developed informal support networks to help them in their grief.
- Moving the bereaved person on multiple occasions during the first year after the death often destroys what informal support network they have. Research has found that following the death of their main carer, people with a learning disability living in the community are likely to be moved on average five times during the first year after the death <sup>(123)</sup>.

Despite these complexities, not every bereaved person with a learning disability will need specialist counselling. However, they will need support from people who:

- are able to be sensitive to their loss and who are open to the fact that it may have reawakened old losses that may not have been resolved
- have a good awareness of healthy grief and who are comfortable with safely facilitating the expression of painful emotions (including anger)
- have some understanding of the impact of a learning disability, and who are comfortable pursuing a developmental model of grief while working age-appropriately with the adult mourner (This may involve working at a very concrete or behavioural level to resolve some of the issues. It will certainly involve careful use of language and constant checking of conceptual understanding.)
- are able to advocate their inclusion in the events that surround the death, eg, planning and going to the funeral

- are able to continue to work with them throughout the entire grieving process – this may be for longer than is generally expected as grief is often delayed and understanding of the process may be patchy.

**Case study:** The Rooots consultancy team ([www.rooots.org.uk](http://www.rooots.org.uk)) help people to understand the issues of bereavement for people with learning disability and have produced a video on this subject. In this, one of the members details his experience of his wife's unexpected death. A few days later he noticed that a group of care staff were 'dressed up' and going out somewhere. When he asked them where they were going they told him that they were going to his wife's funeral. He had not known that it was going to happen that day and as he was not dressed 'appropriately', he was not able to attend the funeral.

Hospices bereavement services should ensure that their services are accessible and appropriate for people with learning disabilities. Professionals with the appropriate expertise should make developing the bereavement care skills of their colleagues a priority, as research suggests that generalist bereavement helpers can be very effective in helping people with a learning disability after only a short training period <sup>(124)</sup>.

No matter how well equipped a service is to meet the needs of bereaved people who have a learning disability, there may be instances when specialist advice or a referral to another service is needed. Therefore, it is important to develop links with the very few specialist bereavement services for people with learning disabilities (see the resources section on page 36 for details). As people with a learning disability experience higher levels of mental ill health (which may be partly related to their bereavement needs not being met), it is advisable to make links also with professionals experienced in the mental healthcare of people with a learning disability.

Details of specialist bereavement services are available from Enfold CIC or Respond (see resources section page 36).

## People with autism

People with a learning disability who have an autistic spectrum disorder are likely to need extra support to deal with their bereavement <sup>(125-128)</sup>.

People with autism can have very high levels of cognitive ability and score highly on IQ tests. However, because of the impact of the autism on their ability to reason abstractly, and on their emotional intelligence, bereavement can be difficult to cope with. So when communicating with a person with autism, it is important to think carefully about the use of language and about how to convey very abstract concepts.

After a death, people with autism may ask very blunt and seemingly unfeeling questions. This can lead to them being misunderstood as not having empathy or being unaffected by the death. However, the loss of routine a death brings can be deeply traumatic for them, so it is important to pre-empt this where possible and to consistently answer seemingly trivial questions like "Who will make my dinner now?" or "How deep is the hole that mum's body was put into?"

New environments can be very challenging for someone with the accompanying sensory distortions of autism. This can mean that hospitals or funerals provide such an array of new smells, sounds and sights that the person may experience 'sensory overload' and be unable to make any sense of the situation. This can result in distressed or distressing behaviour like self-injury. Therefore, on occasion, it may be inappropriate to encourage a person with autism to go to a funeral. If a person with autism is able to go to the funeral, they will need someone with them whose sole responsibility is their support.

See the resources section on page 36 for details of further advice and support on caring for people with autism.



## Children with a learning disability

Children with a learning disability are likely to experience more death (especially amongst their peers) than children from the general population, and thus may require more support.

Supporting a bereaved child who has a learning disability is not necessarily that much more complex than supporting a non-learning disabled child. Generally, it will involve adapting the approach and any supporting materials to the developmental level of the child. However, there may be issues within the family relating to the disability that lead to a complex family response, eg, issues related to attachment and over-protection.

Understandably, many parents do not want to distress their child unnecessarily, and this may be intensified in a family where the child takes longer to understand, or expresses distress through challenging or self-injurious behaviour. Thus there may be a strong desire within the family to keep the knowledge of the illness or death from the child. This is unlikely to result in a good outcome for the child, but families may take some persuading of this, especially since the child will inevitably be distressed by understanding their impending loss.

Currently there is very little written concerning the bereavement needs of learning disabled children,<sup>(129-130)</sup> however, the SeeSaw Grief Support Programme in Oxfordshire has produced a very useful resource pack for professionals<sup>(131)</sup>. (See the resources section on page 36 for more details.)

## Bereaved relatives

Most of the people with learning disabilities that palliative care professionals meet will be relatives of patients, therefore, it is important to include a trigger question in patients' admission interviews to identify whether someone in the family has a learning disability. Failure to do so may mean the person remains hidden until either a crisis develops

or the patient is close to death. It is important to consider proactively the bereavement needs of learning-disabled family members.

The emotional care of relatives bereaved of a learning-disabled patient may also be complicated. It has been suggested that a 'chronic sorrow' can accompany the birth of a child with a disability and initiate feelings of loss for the 'expected' child<sup>(132)</sup>. This, coupled with the impact of 'society's death wish'<sup>(133)</sup> towards people with a learning disability, may mean the relative experiences 'disenfranchised' loss, a loss where the grief is neither expected nor acknowledged by society. People in this situation will need the expert help of counsellors who are able to understand this concept and hospice bereavement services should be aware of this<sup>(134)</sup>.

## Supporting staff in other care settings

The need to support primary healthcare professionals and care staff in settings like nursing or residential homes, staffed group homes and medium secure units cannot be underestimated. As well as advice and support to recognise and assess symptoms and communicate about illness and dying, many care staff may need emotional support, especially those who have never experienced a death before or been involved in caring for someone who is dying.

Several hospices have developed education programmes for care staff. Dorothy House Hospice has a rolling series of education programmes for nursing and residential home care workers, which is co-facilitated by hospice educators, learning disability professionals and service users. Kirkwood Hospice has also developed a programme of educational opportunities for staff involved in all parts of a patient's journey and works with people with a learning disability as co-facilitators.

As well as offering education, hospices and palliative care services can improve the care offered in social care settings by developing 'link workers'.

This is primarily a nursing concept, where a nurse takes a special interest in a particular condition and becomes the information resource for colleagues on this topic. For example, it is common in oncology units to find link nurses in haematology, breast cancer, bowel disease, etc. For palliative care services a learning disability ‘link worker’ would need to learn about assistive communication, issues related to pain and symptom management, and communication of illness to someone with a cognitive deficit. Macmillan Cancer Support has developed a few clinical nurse specialist posts throughout the country for nurses with training in learning disability nursing and palliative care. This is a useful model and similar to link working <sup>(135)</sup>.

However, whilst there is a need to develop specific knowledge about palliative and bereavement care for people with learning disabilities, a move to develop specialisms in the oncological or palliative care of people with a learning disability should be avoided, e.g. a lung cancer nurse for people with a learning disability. This goes against the philosophy of ‘valuing people’ which promotes inclusion rather than segregation, and could also lead to a fragmentation of knowledge and practice, which would reduce the overall standard of care offered to people outside of the care of these professionals.

See the resources section on page 36 for details of a carers’ pack on providing palliative care to people with a learning disability in all settings and a useful publication for residential care staff.

## Transition to adult services

A high proportion of children currently being cared for by children’s hospices have a learning disability as well as their life-limiting condition. It is likely that a significant number of these young people will eventually need adult palliative care services.

The issues for all young people with a life-limiting or life-threatening illness are complex. Fortunately, the topic of ‘transition’ has moved up the government’s agenda significantly in the

recent past and as a consequence there is now some sense of what constitutes a good transition plan. That said, translating this into reality requires appreciably more work, cooperation of services and funding <sup>(136-137)</sup>. The children’s hospice model of care has much to offer adult services that seek to care for young people who are learning disabled and who have a life-threatening illness, particularly by including learning disability professionals in the hospice multi-professional team. Little however has been written specifically on the impact that a learning disability makes on the end of life care of young people and it is hoped that this gap will be addressed in the near future.

At a policy level the government has published a good practice guide for health professionals called ‘Transition: Moving on Well’ (DCSF, DH 2008), which is specifically focused on the needs of young people with complex health needs and/or a disability. It acknowledges the increased difficulties for this client group and the fact that post-16 years there is often a dearth of supportive services, which may have a serious impact on health outcomes.

The more recent Public Health Action Support Team (PHAST) report ‘Transition from children’s to adult palliative care: A Needs Assessment for North East London’ <sup>(138)</sup> highlights the wide range of issues that are involved in transition and the part that hospices can play in meeting them. It says that:

“Following the general principles outlined here, a blueprint begins to emerge of a hospice centre for friendships, stimulation, activities and symptom control and end of life care... As far as the young people are concerned, the messages heard at each hospice interviewed are the same and the requirements are for safe respite care with friends of their own age, education, opportunity for work, a social life, and most importantly independence within the scope of their physical ability.”

The PHAST report also highlights that there is currently little or no provision for the group of young adults with learning disabilities and/or behavioural problems who have complex healthcare needs. It highlights the work of the organisation PAMIS and the 'Transition Planning Tool' <sup>(139)</sup> it has developed, which can be used as a framework to facilitate a systematic approach to planning for the three stages of transition: the preparation, the transition journey itself, and the ongoing care in adult services. This planner helps to track and record all areas of the young person's care such as personal care, health needs, mobility, benefits, and behavioural issues and aims to keep the young person, their families/carers, all professionals (including allied health professionals and social services) involved and well informed. This complements the 'Transition Pathway' previously developed by ACT <sup>(140)</sup>.

One of the most poignant aspects highlighted by the PHAST report is the social isolation that many life-limited young people face. Due to their dependency, and the lack of appropriate support, their ability to maintain a peer network is greatly diminished. It is well known that people with learning disabilities experience much higher levels of loneliness than the general population, but for those who have complex health and communication problems this is likely to be greatly exacerbated and therefore it is vital that adult hospices take this into account when defining what appropriate respite for this client group might include. PHAST suggests that what these young people want is "to be able to live as nearly like their able-bodied peers as possible".

The Transition Partnership, which comprises children's and adult palliative care organisations working together to develop practice and thinking, is a useful source of information. Visit the Help the Hospices website for more information.

See the resources section on page 36 for details of a useful toolkit from Children's Hospices UK on working with diversity.

## User involvement

Hospices are still in the early stages of developing service user involvement and often struggle to elicit constructive criticism. The comparative luxury of hospices in relation to many hospital settings can make it difficult for patients and family members to 'complain' without feeling that they are being 'picky' or unreasonable.

It is hard to imagine how hospices will adapt to include the views of all service users, including those of people with a learning disability (whether verbal or not). Children's Hospices UK has made a good first start by developing a toolkit for hospices to consider the issues related to service user involvement <sup>(141)</sup>. However, the learning disability advocacy movement is probably better developed than current hospice user involvement and may have lessons to offer. Groups such as People First, local Valuing People forums and other local advocacy groups should be invited to participate in hospice discussions on how to make services more accessible and feedback more 'real'. The concept of 'self-advocate' (a self-advocate is one who speaks up for themselves and thereby represents both their own experience and elements of that of others) has been developed as a meaningful role within learning disability and is a model that has a lot to offer hospices at this stage of their development.





# Conclusion

Last summer, 20 years after meeting Maureen (the person whose story opens this book) I spent an afternoon with the GOLD (Growing Older with a Learning Disability) Group. This small group of people with learning disabilities was brought together more than a decade ago, initially to help the Foundation for People with Learning Disabilities understand emerging issues for people with learning disabilities as they age. Once that research was complete it seemed like their purpose for meeting might have come to an end, but as a result of the special bonds individuals had made whilst undertaking this work, and the immense dedication of their facilitators, the group has continued to meet ever since (sometimes with funding and often without). Over the past decade they have contributed significantly to the breadth and depth of professionals' understanding of the 'lived' experience of people with learning disabilities.

The focus of our meeting that afternoon was to consider what people with learning disabilities need from palliative care. The conversation, which was skilfully supported by the group's facilitators, really typified how far we have travelled in the last 20 years, and says something of where we need to go next.

It is clear that there is much to celebrate; indeed the very fact that people with learning disabilities now live long enough to require the services of adult hospices is cause for celebration. However, it is also clear that whilst much of the warp and woof of the

lives of people with learning disabilities is the same as those without, there are also significant differences; for example, the variant disease profile and the high incidence of dementia do need to be given serious consideration.

I was reminded powerfully again that given the chance, and support to do so, most people with learning disabilities are equally able to consider what they want regarding their end of life care. The group that day talked about whether they would want their life prolonged at the cost of having to have lots of interventions and having to stay in hospital. The range of opinions expressed mirrored exactly those of the patients and families I see daily who do not have a disability. They just as ably considered whether they wanted to remain at home to die, but with perhaps a better understanding of what it might be like to be completely dependent on services, family and friends to make this happen; for many of them this is not a new experience.

However, I was also reminded powerfully of the dual sense of powerlessness and fearfulness which is implicit in many people with learning disabilities' stories and which although initiated by their disabilities were not an inevitable consequence of them. Once again I heard accounts of not being 'allowed' to visit loved ones in hospital or to attend their funerals (even those of parents) because being the person with a learning disability you are expected to make a scene, not to cope, or even not to have an opinion or choice.

In a society where eight out of 10 children with disabilities are bullied <sup>(142)</sup>, where disability hate crime is on the increase rather than the wane, and in a professional world where we fail to value people with learning disabilities such that we do not learn from horrifying reports like ‘Death by indifference’ – reading subsequently, five years on, that many, many more people may have died needless deaths under the care of the NHS <sup>(143)</sup> – it is clear that we still have much to learn.

Supported and valued, GOLD group members made clear that if they knew they were dying they would want to:

“Sort out my funeral.”

“Know that I would not be in pain.”

“Have the chance to do things I have never done.”

However there are still too many instances of people with learning disabilities (under-supported and undervalued) dying in pain, distress and without their preferences about care explored, far less actualised. We know these instances can lead to complex grief for family members, an intensifying of fear for peers, as well as an impoverishment of our professional community and reputation.

It is absolutely vital therefore that we work in partnership with those whose skills, tools and knowledge complement and extend ours (be they professionals, family members or other people with learning disabilities), so that the voices of people with learning disabilities can be heard, their choices expressed and all of us empowered to ensure that, wherever humanly possible, we meet their needs, wants and aspirations for their dying and for those who love them. Hospices are uniquely placed to do this – we can be, and often are, light of foot in developing new responses – but only if we take seriously that equitable approaches which adapt, extend and widen our current models of care, and the services which arise from them, are not the stuff of silly trends or naïve ‘political correctness’ but are how we are able, with integrity, to proclaim that what we seek to do (in all service responses) is to demonstrate that:

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

**Dame Cicely Saunders**

# TOWARDS EXCELLENCE IN HOSPICE CARE

# Resources

There are a number of useful resources and organisations:

## Accessible literature for people with learning disabilities who are ill, dying or bereaved

A number of organisations have developed accessible end of life care and bereavement literature. These include:

### Books beyond words

This series of 'wordless' books, developed by St George's Hospital, London, and produced by the Royal College of Psychiatrists, are an aid to practitioners covering a wide range of issues from depression to cancer screening. Pages can be used individually to enable people with learning disabilities to tell their own story or alternatively there is a script at the back of the book that practitioners can use if required. Recent books in the series focus on cancer, 'Getting on with cancer', bereavement, 'When somebody dies' and most recently on palliative care, 'When I die'. For further information on the series visit [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk) and follow the links to the publications section.

### Cancer: What's going to happen to me?

Edition 1, Spring 2011. Words by Alison Chalmers and Edward Nowicki, edited by Edward Nowicki (ISBN 0-9546863-3-0). The Learning Disabilities Federation (North Tyneside), 205 Park Road, Wallsend, Tyne and Wear, NE28 7NL. Tel: 0191 200 1100, Email: [learningdisabilities.federation@virgin.net](mailto:learningdisabilities.federation@virgin.net) From the Learning Disabilities Federation, this accessible publication was developed with the involvement of service users.

### Change

Change People is a social enterprise based in Leeds, which works with people with learning disabilities as consultants. Change has developed a line

drawing picture bank, which services can use to make their in-house literature accessible. Services purchase an annual licence that gives them access to the picture library. Change has also developed a number of accessible resources on aspects of cancer care for people with learning disabilities. For more information visit [www.changepeople.co.uk](http://www.changepeople.co.uk) The set of three cancer books cover the subjects, 'Symptoms, Screening and Health', 'Diagnosis and Treatment', and 'Palliative and End of Life Care And Bereavement'. They can be ordered free of charge from the Macmillan Cancer Support website or by telephoning 0800 500 800.

### Family Advice and Information Resource (FAIR)

This Edinburgh-based organisation has developed, in consultation with people with learning disabilities, a range of accessible, easy read booklets and CD ROMs on various types of cancer. For more information or to view the range of resources visit [www.fairadvice.org.uk](http://www.fairadvice.org.uk) or phone 0131 662 1962.

### Down's Syndrome Scotland

DS Scotland has developed an easy read book called 'Let's talk about death: a booklet about death and funerals for adults who have a learning disability'. For more information visit [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

### Cancer and you toolkit

Kate Provan, Trafford PCT, developed this toolkit. As well as identifying relevant resources to explain cancer to people with learning disabilities, it also modifies the Macmillan model of information provision to consider the issues involved in communicating with people with learning disabilities in a section on the 'mode of information giving'. This resource is useful in helping practitioners to identify accessible information and to think about the best ways in which to deliver the information to meet people's communication needs. For more information visit the Valuing People website at [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)



## The Hospital Communication Book

Developed on behalf of the learning disability partnership board in Surrey, this document aims to help people who have difficulties understanding or communicating to get equal service in hospital. It includes Makaton symbols so that mainstream staff can both understand and use these in their interactions with people with learning disabilities. This document can be downloaded from [www.communicationpeople.co.uk](http://www.communicationpeople.co.uk)

## Dementia resources

There are a number of resources that focus specifically on the dementia care of people with learning disabilities. These include:

### **Down's syndrome and Dementia – Workbook for Staff (2006)**

Dodd K, Kerr D, Fern S. Down's Syndrome Association, London. This workbook is primarily for support staff working with people with Down's syndrome who have dementia. It aims to enable staff to offer specific individuals the most effective care possible as their condition progresses and their needs change. For more information visit [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

### **Persons with intellectual disability and dementia: fusing the horizons of intellectual disability, palliative and person-centered dementia care. An introductory education and training programme**

Fahey-McCarthy E, McCarron M, Connaire K, McCallion P (2008). This extensive training pack includes a trainers' manual, CD ROMs and student reflective work book and covers a wide range of issues related to the palliative and end of life care for people with learning disabilities who have dementia. For further information contact Annabel Walsh, Research Executive Officer, School of Nursing and Midwifery, The University of Dublin Trinity College, 24 D'Olier Street, Dublin 2. Tel: + 353 1 8962775, Fax: + 353 1 8963001, Email: [annabel.walsh@tcd.ie](mailto:annabel.walsh@tcd.ie) [www.nursing-midwifery.tcd.ie](http://www.nursing-midwifery.tcd.ie)

## Dementia and People with Learning Disabilities

From Respond, DSA and the Valuing People Team (2008). This invaluable training pack has been devised by Respond (an organisation providing psychotherapeutic interventions for people with learning disabilities) in partnership with the Growing Older with Learning Disabilities (GOLD) group – a group of older people with learning disabilities who have been working together for the past decade on helping others to understand what it means to grow older with a learning disability. The focus for this training pack is the importance of supporting the relationships of people with learning disabilities who develop dementia. It is aimed at the staff team of a residential home but is flexible for other training situations. Individual information cards can be copied and used as handouts or to plan teaching sessions. The action cards can be used as the basis for small group exercises. The pack also contains two DVDs – the original GOLD video which covers aspects of growing older with a learning disability, and 'Forget me not', a play about dementia from the perspective of people with learning disabilities. The play has been devised and performed by the GOLD group. There is also a reading and resource list. For further information about this pack or training delivered by Respond on dementia and learning disability visit [www.respond.org.uk](http://www.respond.org.uk)

### **Leicestershire Partnership Trust NHS Dementia Focus Group**

Members of the multi-professional team within the Learning Disability Service, along with carers and service users, have developed a 'Dementia Care Pathway', a 'Carer's Information Pack' and an 'End of Life Package'. This work, which has been piloted by service users, is full of useful information and signposts to other resources. For copies of these publications please contact: Jennifer White, Community Learning Disability Nurse Manager at [jennifer.white@leicspart.nhs.uk](mailto:jennifer.white@leicspart.nhs.uk) or Tracey Finnamore, Practice Development Nurse at [tracey.finnamore@leicspart.nhs.uk](mailto:tracey.finnamore@leicspart.nhs.uk)

## Accessible advance care planning tools and resources

### Advanced directive/end of life care plan for people with learning disabilities

Produced by the learning disability section of Gloucestershire Partnership Trust, this document covers capacity, medical interventions, DNAR, palliative care needs and quality of life issues. There is also a booklet for patients to complete, 'My end of life book', which can be downloaded from the website. For more details contact Gloucestershire Partnership Trust on 0800 019 3346 or visit [www.partnershiptrust.org.uk](http://www.partnershiptrust.org.uk)

### Assessment of capacity pro-forma for people with learning disabilities

Also produced by Gloucestershire Partnership Trust, this document aims to record step by step the process of assessing capacity to consent to treatment. It details non-verbal communication as well as verbal communication. For more details contact Gloucestershire Partnership Trust on 0800 019 3346 or visit [www.partnershiptrust.org.uk](http://www.partnershiptrust.org.uk)

### When I die

Document developed by Calderstones NHS Trust and produced by Heywood and Middleton Primary Care Trust. This is an easy read document that aims to help people express their wishes about what they would like to happen when they die, eg, choices about funerals. For further information visit [www.calderstones.nhs.uk](http://www.calderstones.nhs.uk) or Manchester PCT Learning Disability Partnership on 0161 998 7424.

### My thinking ahead and making plans

This is a document which has been devised by Dr K Boyd, and Professor S Murray of the University of Edinburgh to help people to take control and make their voices heard. Written in easy read English, the plan is designed to guide people through

thinking about what is important to them in the present and the future. It can be downloaded from [www.palliativecareggc.org.uk](http://www.palliativecareggc.org.uk)

### My end of life book guidance

An easy read document to guide staff supporting a person through decision making with regard to end of life. The booklet covers issues such as a funeral preference and wills. It can be adapted without permission and can be downloaded from [www.partnershiptrust.org.uk/pdf/helthfacilitation/myendoflifebookguidance.pdf](http://www.partnershiptrust.org.uk/pdf/helthfacilitation/myendoflifebookguidance.pdf)

## Useful organisations

### A2A Access to Acute Hospital Network

The acute liaison nurse network is mainly concerned with the issues surrounding people with a learning disability, their carers and staff in the general hospital. The A2A network was formed in 1998 and has expanded to become a national network for those who support people with a learning disability when they are in a general hospital. This may be as an outpatient or on admission (emergency or elected). The National Patient Safety Agency identified the vulnerability of people with a learning disability in the general hospital as a key area of risk.

Membership is open to anyone who has an interest in this area of work, but mainly includes nurses who work in the field of learning disability, with some staff who work in the general hospital. The network is closely affiliated to others in learning disability (UK Primary Care Network, Mental Health in Learning Disability) and also with the Valuing People Support Team. For more information visit [www.nnldn.org.uk/a2a](http://www.nnldn.org.uk/a2a)

### (ARC) Association for Real Change: National Ethnicity and Learning Disability Network

A Department of Health-funded project to set up and run a good practice/information sharing network on all initiatives concerned with learning

disability and ethnicity. The project produces four newsletters a year and hosts an annual conference as well as facilitating networks and information sharing among interested parties. For more information phone 01246 555 043, contact 1 ARC House, Marsden Street, Chesterfield, Derbyshire, S40 1JY, England, or visit [www.arcuk.org.uk](http://www.arcuk.org.uk)

### **Down's Syndrome Association**

The website includes a wealth of information about Down's syndrome. The service also provides an information helpline. For more information visit [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

### **Elfrida Society**

Researches support for people with learning disabilities and provides a wide range of accessible information on health issues. See [www.elfrida.com](http://www.elfrida.com)

### **Enfold C.I.C**

This social enterprise seeks to provide information and advice on issues related to the end of life and bereavement care of people with learning disabilities, and training, consultancy and supervision for staff. The website for this organisation is currently under construction but further information can be gained by emailing [Info@enfold.org.uk](mailto:Info@enfold.org.uk)

### **The Estia Centre**

A centre that specialises in the mental health needs of people with learning disabilities. See [www.estiacentre.org](http://www.estiacentre.org)

### **Foundation for people with learning disabilities**

Part of the Mental Health Foundation, it aims to promote information and learning about people with learning disabilities. It hosts a number of forums such as the UK Health and Disability Network (see below) and provides a summary of relevant news stories for practitioners. The foundation has produced reports on spirituality, palliative care, and supporting older families. For more information visit [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

### **Getting it right**

A project developed by several health professional bodies to help improve healthcare for people with learning disabilities. See [www.mencap.org.uk/gettingitright](http://www.mencap.org.uk/gettingitright)

### **Learning Disability Observatory (Improving Health and Lives)**

This observatory was set up as a result of the inquiry into the deaths of six people first identified in the Mencap 'Death by Indifference' report. The observatory seeks to investigate the health and healthcare of people with learning disabilities using information contained in official or NHS statistics. See [www.improvinghealthandlives.org.uk](http://www.improvinghealthandlives.org.uk)

### **National Autistic Society**

Aims to champion the rights and interests of all people with autism and to provide individuals with autism and their families with help, support and services that they can access, trust and rely on, and which can make a positive difference to their lives. The NAS website provides information about autistic spectrum disorders (including Asperger's syndrome) and about services and literature. For more information visit [www.nas.org.uk](http://www.nas.org.uk)

### **National Health Facilitation Network (Learning Disabilities)**

Aims to share information, resources and good practice to improve the process of health facilitation for people with a learning disability. Originally formed in early 2005 as an email network, the National Health Facilitation Network aims to freely share knowledge, experiences and skills relating to health facilitation as described in 'Valuing People' (2001). As well as by email, this is done through conferences and the provision of a full contacts list for members to communicate directly with other members. Membership is free and there is no allocated funding for the network. For further information contact Mark Bradley on 0208 269 3349 or email [mark.bradley@oxleas.nhs.uk](mailto:mark.bradley@oxleas.nhs.uk)

### **Inclusion Ireland (formally Namhi)**

A voluntary organisation working to promote the rights of people with intellectual disability (learning disability) in Ireland, to ensure their full and equal participation in society. It coordinates more than 160 separate organisations and acts as a central forum for members to identify priorities and formulate nationally agreed policies to present to government. See the publication 'Alzheimer's dementia in persons with intellectual disability: some common questions and concerns'. For more information contact [www.ssess.ie/links/special-education/-/disability-sites-ireland/inclusion-ireland-formerly-namhi](http://www.ssess.ie/links/special-education/-/disability-sites-ireland/inclusion-ireland-formerly-namhi)

### **National Network for Learning Disability Nurses (NNLDN)**

The National Network for Learning Disability Nurses helps learning disability nurses in the UK and Ireland to share their experiences, access information, network with each other, engage in dialogue on current issues and disseminate sound practice and research.

The NNLDN is a 'network of networks' which aims to support networks and nurses within the field of learning disability. It facilitates networking and sharing of practice, promotes user and carer perspectives, encourages information exchange and engages with central bodies to highlight needs and achievements within learning disability nursing. Through its Core Group, consisting of representatives of active networks, it works to assist networking wherever it can and in particular by maintaining an up-to-date contact list of known regional networks. It aims to encourage a high level of cross-UK awareness of the learning disability nursing enterprise, in particular in relation to practice. For more information visit [www.nnldn.org.uk](http://www.nnldn.org.uk) or contact Meadhbh Hall at [meadhbh.hall@ntlworld.com](mailto:meadhbh.hall@ntlworld.com)

### **Palliative Care of People with Learning Disabilities Network (PCPLD)**

This voluntary, membership organisation aims to provide information, support and training for carers of people with learning disabilities who have palliative and/or bereavement care needs. There are several area groups throughout the UK and the Republic of Ireland whose members meet regularly to collaborate to develop research, good practice and support members in their individual areas of work. It draws members from all professions as well as from family carers and a small number of people with learning disabilities with a special interest or experience in this area. The PCPLD provides two national study days each year and two newsletters to keep members up to date with developments in the field. For further information visit [www.pcpld.org](http://www.pcpld.org)

### **PAMIS**

PAMIS works with and for people with profound and multiple learning disabilities (PMLD) that have a range of complex needs including profound learning disabilities, extreme physical disabilities, sensory impairments, non-verbal communication and very complex health problems. Priority is given to trying to provide support to family carers and this is carried out through a dedicated family support service. Additionally intensive support is given to family carers through the difficult and often stressful period of transition from children to adult services through the transition pathways and futures project. PAMIS also has a specialist information and library service that provides specialist advice and information on all areas concerning complex disabilities.

## People First

An organisation run by and for people with learning disabilities to raise awareness of, and campaign for the rights of, people with learning disabilities, and to support self-advocacy groups throughout the country. See [www.peoplefirstltd.com](http://www.peoplefirstltd.com)

## UK Health and Disability Network

A network open to anyone with an interest in health and learning disability issues. Members come from all backgrounds including families, self-advocates and agencies working with people with a learning disability, nurses, GPs, psychologists and therapists. The network aims to help health practitioners in both mainstream and specialist services with the health and learning disability agenda. It concentrates on problem-solving, information sharing and networking. Further information is available from the Foundation of People with Learning Disabilities website at [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk) or from Janet Cobb, who coordinates the network, by emailing [jcobb@fpld.org.uk](mailto:jcobb@fpld.org.uk)

## Values into action

Provides research, training, outreach and accessible information. See [www.viauk.org](http://www.viauk.org)

## Respond

Provides high-quality psychotherapeutic interventions for people with learning disabilities who have experienced trauma. Originally working solely with victims and perpetrators of sexual abuse, Respond now also offers one-to-one and group support, a helpline, training and consultancy on issues related to ageing, dying and bereavement of people with learning disabilities. For further information visit [www.respond.org.uk](http://www.respond.org.uk) or contact [admin@respond.org.uk](mailto:admin@respond.org.uk) or phone 020 7383 0700.

## Useful websites

### Easyhealth

This website brings together accessible resources on health issues affecting people with learning disabilities. A relatively new website, it continues to develop. For more information visit [www.easyhealth.org.uk](http://www.easyhealth.org.uk)

### Help the Hospices e-learning

Help the Hospices website hosts the CLIP tutorials (Current Learning in Palliative Care). These 15-minute tutorials can be completed on-line or downloaded for use personally or by tutors. Many of these workshops have been co-written by palliative care and learning disability professionals including a specific section on the palliative care of people with learning disabilities.

The tutorials are accessed via the education and training section of the website [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

### Intellectual Disability Health Information

Provides information on the health needs of people with learning disabilities. See [www.intellectualdisability.info](http://www.intellectualdisability.info)

### Learning Disability Specialist Library

A branch of the National Library for Health that aims to bring together and make available the best current evidence to support decision makers in supporting people with learning disabilities. See [www.library.nhs.uk/learningdisabilities](http://www.library.nhs.uk/learningdisabilities)

### Manchester Learning Disabilities Partnership Board

The Partnership Board, which encourages personal independence so that people can work out and achieve what they want, have produced a series of end of life care pathways. See [www.mldp.org.uk/documents/WHENIDIE\\_ENDOFLIFECAREPATHWAYS.pdf](http://www.mldp.org.uk/documents/WHENIDIE_ENDOFLIFECAREPATHWAYS.pdf)



### **Mencap's website**

Mencap has received funding from the Department of Health to provide health information for people with learning disabilities. Their website has a high level of accessibility for users who have cognitive deficits. For example 'You and your health: a basic guide to being healthy' has an easy read format and covers issues about diet, looking after your body and health checks. For more information visit [www.mencap.org.uk](http://www.mencap.org.uk)

### **NottsInfoScript.co.uk**

Nottinghamshire's Information Prescription Team has developed accessible information prescription resources which can be downloaded from [www.nottsinfoscript.co.uk](http://www.nottsinfoscript.co.uk)

## **Further reading**

### **Best Interests at End of life: Practical Guidance for Best Interests Decision Making and Care Planning at End of Life**

Authors Hutchinson C, Foster J (2008). Commissioned by SCIE, this publication provides a useful resource for practitioners to work through the issues related to end of life care decision making in compliance with the Mental Capacity Act. Utilising case study examples the text helps readers to understand the issues they need to consider when acting in the 'best interests' of service users.

### **Caring for people with learning disabilities who are dying**

Authors Todd S, Blackman N Worth Publishing, London (2005).

### **Dignity in health care for people with learning disabilities**

Royal College of Nursing (2010). This publication provides guidance to improve dignity in healthcare for people with learning disabilities. The core themes of the publication are: what does dignity mean? What are people with learning disabilities' experience of health services? What could nurses do to enhance patients' dignity? It signposts to a range of helpful resources and organisations. This publication can be downloaded from [www.rcn.org.uk](http://www.rcn.org.uk)

### **Dying Matters: A workbook on caring for people with learning disabilities who are terminally ill**

Authors Brown H, Burns S, Flynn M (2005), Pavilion, London. This publication is aimed at residential care staff looking after people with learning disabilities who are terminally ill.

### **Equal access: A practical guide for the NHS**

Concerned with the creation of a single equality scheme that includes improving access for people with learning disabilities, and published by the Department of Health (2009), this guide supports the NHS to include people with learning disabilities in their equality schemes, with practical examples of reasonable adjustments to achieve equity of access.

### **End of Life Care: A guide to offering care and support to people with a learning disability at the end of life**

This resource pack is aimed at anyone in the range of professionals likely to support people with learning disabilities and their carers at the end of life. (NHS End of Life Care Programme, NHS North East, 2007). Can be downloaded from the National End of Life Care Programme website at [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

## Health A-Z

An A to Z of healthcare issues affecting people with learning disabilities, compiled by Esia Dean and available from the Valuing People website at [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)

## How people with learning disabilities die

Authors Glover G, Ayub M. Learning Disabilities Observatory report into the mortality of people with learning disabilities based on evidence from death certificates of all those registered dead within England 2004–2008. The report can be downloaded from the Learning Disability Observatory website. See [www.improvinghealthandlives.org.uk](http://www.improvinghealthandlives.org.uk)

## List of clinical syndromes linked to learning disabilities and health issues they present

A document that aims to increase the knowledge of generalist healthcare professionals on the physical syndrome-related issues that people with learning disabilities face. Produced by West Sussex Health and Social Care Trust. Copies are available from the author Cath Scott by email at [cath.scott@wshsc.nhs.co.uk](mailto:cath.scott@wshsc.nhs.co.uk)

## Meeting the health needs of people with learning disabilities: guidance for nursing staff

This Royal College of Nursing publication can be downloaded for free from [www.rcn.org.uk](http://www.rcn.org.uk) It is a comprehensive document which is particularly valuable for the advice it gives on how to make services and environments accessible for people with learning disabilities.

## Palliative care for people with learning disabilities

Edited by Read S, Quay books, London (2007). This book brings together leading practitioners in the palliative care of people with learning disabilities and includes a good introduction to the issues for practice.

## Promoting access to healthcare for people with a learning disability – a guide for frontline NHS staff

This guidance, produced by NHS Quality Improvement Scotland, covers a range of issues including: staff attitude and identification of additional needs; communication; arrangements and structures to facilitate access; education and training; telephone protocol; tips for good oral communication; tips on producing written material; using signs, symbols and photographs; principles of informed consent; and an audit tool on access to healthcare. Copies can be downloaded from [www.nhsquality.org](http://www.nhsquality.org)

## The route to success in end of life care: achieving quality for people with learning disabilities (2011)

Produced by the National End of Life Care Programme, this document follows the same format as the other 'routes to success' publications. It seeks to enable readers to consider the specific issues for people with learning disabilities at each stage of the end of life care pathway. It includes good practice case studies and quotes from service users to illustrate the points.

## Treatment and care towards the end of life: good practice in decision making

Published in 2010 by the General Medical Council, this publication guides practitioners through the process of dealing with issues relating to end of life care decision making.

TOWARDS  
EXCELLENCE  
IN HOSPICE CARE

# Glossary of terms

## Acute liaison nurses

Acute liaison nurses are employed to enable people with particular conditions to receive the most appropriate care. They do this by being a resource of knowledge and information, to be shared with generalist staff, and to act as a link between staff and the patient. The acute liaison nurse role is similar to that of the health facilitator, which aims to enable people with learning disabilities and their families to navigate the systems of the NHS. Their role is a wide and varied one and includes both reactive elements (e.g. being called to the accident and emergency section of a hospital when someone with a learning disability is admitted) and proactive elements (e.g. preparing a person with learning disabilities for a breast screening appointment and helping staff to understand the patient's communication needs). The role is also an educative one as the liaison nurse will help to train generalist staff about the communication or symptom assessment issues for people with learning disabilities. Not all hospitals have invested in this role but where they have, it can benefit both staff and patients. It can also reduce the numbers of complaints that the trust receives as the result of inadequate or discriminatory treatment. The role is well described in Garvey's article on setting up a learning disability acute liaison team <sup>(144)</sup>. Further details on acute liaison nurses and their locations are available from the A2A Network (see Resources section page 36).

## Assistive communication aids

Assistive communication aids are equipment or techniques used to communicate with someone who does not use verbal speech. These aids can be quite simple such as a sign or symbol board that enables the person to communicate their need for food, drink, toilet, or to ask for a special person or pet. They can be more sophisticated, such as 'light writers', which convert typed words or eye movements into simulated speech, e.g. the machine used by Professor Stephen Hawkins.

## Autistic spectrum disorders and Asperger's syndrome

Autism is a lifelong developmental disability. It is sometimes referred to as an autistic spectrum disorder (ASD). The word 'spectrum' is used because, while all people with autism share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'normal' lives while others will require a lifetime of specialist support. The three main areas of difficulty that all people with autism share are sometimes known as the triad of impairments. They are: difficulty with social communication, difficulty with social interaction, and difficulty with social imagination.

Many people with autism need a high level of routine to function securely. Therefore a bereavement will need to be supported by maintaining as much 'normality' as possible, e.g. with meal times, school or work attendance. A significant number of people with ASD also have heightened sensory perception, therefore noises, lights and smells can be very distressing to them – touch and eye contact can also be overly stimulating. In these situations careful thought needs to be given to new environments such as hospitals or even funeral attendance. Some people with ASD are also prone to 'obsessional' behaviours and find these very comforting; such behaviours increase during times of distress, therefore consideration should be given to how to facilitate the safe expression of these in the care environment. Many people with learning disabilities also have ASD.

Asperger's syndrome is a form of autism. People with Asperger's have fewer problems with speaking and are often of average, or above average, intelligence. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties. These may include dyslexia and dyspraxia, or other conditions such as attention deficit hyperactivity disorder (ADHD) and epilepsy.

## Content behaviours

Content behaviours are those expressed ordinarily by the person (when 'content') and therefore are those which are least likely to be associated with distress. It is important to recognise that each individual has their own distinct repertoire of content behaviours which are 'normal', non-distressed behaviours for them, eg, sucking a thumb may be a content behaviour for one person but signify distress for another.

In trying to find out the expressions of distress in a non-verbal person with learning disabilities, (one cause of which may be physical pain) it is important to record (preferably pre-illness) content behaviours to determine a baseline to measure deviance against, e.g. the deviance from low pitched humming sounds to high-pitched screaming sounds or from still to rocking movements. Distress may be expressed in terms of new or different behaviours but may also be expressed as an absence or reduction of the usual content behaviours, e.g. less rocking rather than more.

## DisDAT

The Disability Distress Assessment Tool (DisDAT) is one method of recording a baseline of signs and behaviours when content and against which changes can be monitored when the person is distressed. Developed to be used with people with a learning disability it is particularly useful with people who do not use verbal speech, though it has the potential for wider application.

When a behaviour change occurs, it should be checked against previous known episodes of distress and the circumstances in which they occurred. These distress signs and behaviours can then be evaluated alongside the DisDAT clinical decision-making checklist so when the likeliest cause of distress (e.g. pain) is identified, interventions are made to help

alleviate the distress. The signs and behaviours are then reassessed to see whether they have returned to the baseline 'content' behaviours. If the distress signs and behaviours have not reduced or stopped, then the carer returns to the clinical decision-making checklist to re-evaluate the previous hypothesis for the behaviour. Alternative interventions are then offered on this basis until the distress is alleviated, which is shown by a return to the baseline behaviour. Copies of the DisDAT tool (and accompanying guidance notes) can be downloaded from [www.disdat.co.uk](http://www.disdat.co.uk) and from the NHS National End of Life Care Programme website [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

## Healthcare facilitators

Healthcare facilitators are a professional group developed in response to the government white paper on people with learning disabilities 'Valuing People' (DH 2001) <sup>(145)</sup>. These staff are drawn from local community learning disability teams to support people with learning disabilities to access the healthcare they need from primary care and other NHS services. It is expected that learning disability-trained nurses will primarily carry out this role, part of which is to help GPs identify their learning disabled patients (with help from social services, education and other health professionals).

The healthcare facilitator's role is to advocate for the client, to make sure that they receive full access to the range of healthcare services available, and to enable clients to navigate their way around the health service. In Scotland, the healthcare facilitator role is known as the local area coordinator. The Department of Health has developed a good practice guide for health facilitation and health action planning. For more information visit [www.info4local.gov.uk/documents/publications](http://www.info4local.gov.uk/documents/publications)

## Health action plans

Health action plans have been developed in response to the government white paper on learning disability 'Valuing People' (DH 2001). The health action plan (HAP) is a document detailing a person's needs in regard to health interventions including oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of any medication taken, side effects and records of any screening tests. These HAPs will be reviewed as part of the recommended annual health check for people with learning disabilities as well as at key points of transition in the person's life, e.g. move from one care agency to another or on retirement. Further information can be found on the Valuing People website [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk). The Department of Health has developed a good practice guide for health action planning and health facilitation. For more information visit [www.info4local.gov.uk/documents/publications](http://www.info4local.gov.uk/documents/publications)

## Indicators of learning disability

The West Sussex Learning Disability Team has suggested that indicators of a learning disability might include the following elements:

- A history of being excluded/suspended from mainstream school.
- Case notes which refer to special school history.
- Previous formal assessment of level of functioning (psychology report).
- Clinical notes from various areas, which present a picture of difficulties in a number of areas of adaptive behaviour not explained by an alternative label, e.g. mental health.
- Has reading and maths skills up to grades 3–6 but rarely beyond.

- Unable to acquire complex practical and vocational skills.
- Other family members diagnosed with a learning disability.

They further suggest that elements which may suggest the person does not have a learning disability are:

- School exam results higher than expected, and attended mainstream education without education support.
- Employment history shows the person coping without expected levels of support.
- Suggestion of onset of problems post-18.
- Variable amount of support is needed.
- The person holds a driving licence/drives a car.
- They complete complex purchases without help.
- Person showed age-appropriate development until head injury or accident.
- Person showed age-appropriate development until chronic mental health problems.

Of course there are people with learning disabilities who hold a driving licence and there are others whose struggle has been hidden from professionals until the crisis of illness. However, these indicators are a good starting point for a dialogue. Other questions may be asked about formal and informal networks, as these might give an indication of levels of unseen support, which enables the person to compensate for or disguise their learning disability. For example, does the person have a non-disabled partner or a highly involved sibling?

For further information contact Jenny Webb, Consultant Clinical Psychologist, Community Team for People with a Learning Disability, 72, Stockbridge Road, Chichester, PO19 8QJ or email [jenny.webb@sussexpartnership.nhs.uk](mailto:jenny.webb@sussexpartnership.nhs.uk) (phone 01243 813 400).



## Learning disability and learning difficulty

Learning 'disability' is described by the Department of Health as 'a state of arrested or incomplete development of mind which began in childhood and which includes significant impairment of intellectual and social functioning' (DH 2001). However, a learning 'difficulty' usually indicates specific problems such as dyslexia and dyspraxia. Some organisations subscribing to a social model of care would argue that people have impairments and that it is society which 'disables' them by making it difficult to access an 'ordinary' life. They would therefore suggest that a person does not have a disability of mobility but that they have mobility impairment and society disables them by not providing fully accessible transport systems. Such organisations would not ascribe 'disability' to the person and would therefore describe people as having 'learning difficulties' and may object to the term 'learning disability'. Some people with learning disabilities who would prefer to be described as having a learning difficulty to avoid the stigma associated with disability echo this. It can be confusing when practitioners use the terms interchangeably to describe a lifelong condition rather than specific difficulties of learning such as dyspraxia and dyslexia.

## Makaton

Makaton is a type of sign language used by many people with learning disabilities. It is a much simpler signing system than British Sign Language and uses gestures that convey understanding almost through a pictorial representation. Therefore, it is limited in the information it can convey. However, it is useful for trying to find out some aspects of a person's understanding and mood as it has symbols for illness, pain, death and a limited range of emotions such as happy, sad and angry. For further information visit [www.makaton.org](http://www.makaton.org)

## National service frameworks

Developed by the Department of Health, national service frameworks (NSFs) are a systematic approach to improve standards and quality across healthcare sectors. NSFs were introduced to address variations in standards of care and to achieve greater consistency in the availability and quality of services by establishing mechanisms which enable care to be provided to all. NSFs are implemented in partnership with social care and other organisations. NSFs:

- set national standards and identify key interventions for a defined service or care group
- put in place strategies to support implementation
- establish ways to make sure progress is within an agreed time scale
- form one of a range of measures to raise quality and decrease variations in service, as introduced in 'The New NHS' (DH 1997) and 'A First-Class Service' (DH 1998).

'The NHS Plan' (DH 2000) re-emphasised the role of NSFs as drivers in delivering the modernisation agenda. There will usually be only one new framework developed each year, each of which is developed with the assistance of an external reference group (ERG), bringing together health professionals, service users and carers, health service managers, partner agencies, and other advocates. ERGs adopt an inclusive process to engage the full range of views. The Department of Health supports the ERGs and manages the overall process. For further information visit [www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks](http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks)

Since people with learning disabilities encounter the same health conditions as the general population, it is important to consider the relevant NSF for the condition they have as well as their learning disability. Guidance on the application of the NSFs to people with learning disability can be found on the Valuing People website [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)

## Person-centred planning

The Circles Network describes person-centred planning (PCP) as ‘a process of life planning for individuals, based around the principles of inclusion and the social model of disability’. The process uses a number of tools which aim to make sure that care is individualised to the person. They place an emphasis on facilitating the deepest wishes and dreams of the person, irrespective of their disability. When it works as it should, the process, as well as the product (i.e. the person-centred plan), is owned and controlled by the person, and sometimes their closest family and friends. The plan should be a comprehensive portrait of who the person is, what they want to do with their life, and brings together all the people who are important to the person, including family, friends, neighbours, support workers and other professionals involved in their lives. Some PCPs involve a ‘circle of support’ as part of the process: this is a way of formalising the various types of support the person has in their life into a network, which enables each aspect of the PCP to be met.

The Circles Network suggests that ‘person-centred planning replaces more traditional outmoded styles of assessment and planning which are based on a medical model approach to people’s needs’. For further information visit [www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)

A number of organisations have developed resources to support PCP initiatives. The British Institute of Learning Disability has produced a useful factsheet describing what PCP is and is not – visit [www.bild.org.uk](http://www.bild.org.uk) – and the Valuing People website has a dedicated section on PCP, at [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)

For those professionals who engage with people with a learning disability at the end of their lives, the PCP may give a good indication of the wishes, values and concerns of the patient. Therefore, it is important to include the PCP in any advanced care planning, advanced directive or advanced statement relating to treatment and end of life care.

## Signalong

Signalong is an alternative sign language (based on British Sign Language) which is preferred to Makaton by some agencies. For further information visit [www.signalong.org.uk](http://www.signalong.org.uk)

## Snoezelen

The Snoezelen technique was developed in the Netherlands in the 1970s by institutions caring for severely disabled people. Snoezelen is a multi-functional concept involving a purpose-designed room (most often a ‘white room’) along with the use of light, sound, texture, scents and music to initiate pleasant physical sensations. These can have both relaxing and activating effects on different perception areas. Snoezelen can induce calm and a feeling of wellbeing, and in this sense is therapeutic. However, there is little evidence-based research into the therapeutic effects of Snoezelen, but there is limited evidence of its positive impact on expressions of distress or aggression in people with severe learning disabilities because of this it has been used in some centres to help alleviate distress caused by physical pain. For further information visit [www.isna.de](http://www.isna.de) and [www.rompa.com](http://www.rompa.com)



# Appendices

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